

**FIRST INTERNATIONAL ON-LINE MEETING OF FAMILIES WHO HAVE CHILDREN WITH DUCHENNE AND BECKER MUSCULAR DYSTROPHY**

**DRAFT AGENDA**

**Thursday, March 12**

* **11:30 registration and on-line registration of participants**
* **12:00 Welcome and introduction**

 **Yulya Moskalenko, NGO `Duchenne Ukraine`**

* **12.15 Problems and a good practice in the Inclusive Resource Center in the town of Kropyvnytskyi**

 **Olena Doroshenko, director of the Inclusive Resource Center in Kropyvnytskyi, Ukraine**

* **12.30 The situation with the treatment and a good practice in Australia.**

**Deb Robins, Voluntary Ambassador FNO at Muscular Dystrophy Queensland**

* **13.00 Questions- answers of participants**
* **13.10 The situation with the treatment and a good practice in Israel**

**Mila Gumanovsky, coordinator of 'Little steps', Israeli parents organization**

**13.40 Questions- answers of participants**

* **13.50 The situation with the treatment and a good practice in Czech Republic**

**Pavlina Golubovsky, chief of the organization `End Duchenne`**

**David Petrasek, the member of the organization `End Duchenne` and the brother of the adult wth Duchenne.**

* **14.20 Questions- answers of participants**
* **14.30 The situation with the treatment and a good practice in the Germany**

**Anastasia Semenova, Emil&Henry Charity, Member.**

* **15.00 Questions- answers of participants**
* **15.10 The experience of the Sheikhs family from Pakistan with 4 children, suffering from muscular dystrophy.**

**Hassan Sheikhs, one of the sons of the Sheikhs family. He lives and gets the treatment in Belgium now.**

* **15.25 Questions- answers of participants**
* **16.00 The fight with Duchenne, the story of Billy from USA.**

**Terry Wesley Ellsworth, the mother of Billy**

* **16.20 Questions- answers of participants**

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